The Canadian experience of alternative models of service delivery: Practical guidance for genetic counsellors

Table of Contents

Introduction	
Executive summary	
Decision Aids	6
Evaluation Tools	8
Genetic Counselling Assistants	12
Group Genetic Counselling	
Mainstreaming	
Patient portals	22
Telehealth Genetic Counselling	24
Webinars	30
Videos	32
Conclusion	35
Resource persons among CAGC members	37
References	39

Executive summary

A perceived need to better understand the use of alternative models of genetic counselling service delivery in Canada led the Canadian Association of Genetic Counsellors (CAGC) to create a new Community of Practice (CoP) group in 2020. The aim of the CoP was to promote a national collaboration for sharing knowledge regarding the creation, delivery and evaluation of alternative models of genetic counselling care. The document, developed on the basis of the work of this group: The Canadian experience of alternative models of service delivery: Practical guidance for genetic counsellors, is an openly available resource as a reference on the subject for CAGC members.

Increased awareness, testing options and demand for genetic counselling (GC), along with the limited numbers of genetic counsellors has led to compromised accessibility and long wait times for patients in many genetic clinics. This situation has led to the development and implementation of alternative models of genetic counselling deviating from the traditional model whereby a genetic counsellor meets with a patient one-on-one for pre-test counselling and then again for post-test counselling. The implementation of innovative models of GC service delivery may increase service efficiency, improve patient access to services and sustain the practice of genetic counsellors.

The alternative models which are described in the 2024 version of this document or will be included in a near future draft include (in alphabetical order):

- 1) <u>Chat bots</u>: A genetic counseling chatbot is an artificial intelligence computer program which can simulate human conversation with a patient with the goal of providing information and responding to questions.
- 2) <u>Decision Aids</u>: These refer to tools or resources that are designed to assist patients and healthcare providers in making informed decisions about their health care and treatment options, by providing evidence-based information and values clarification about available options, benefits, risks and outcomes.
- 3) Genetic counselling assistants: GCAs are non-clerical staff who are generally not responsible for direct clinical care but primarily perform 'behind the scenes' coordination and administrative tasks traditionally assigned to genetic counsellors.
- 4) <u>Group genetic counselling</u>: This is generally defined as a genetic counsellor providing in person pretest counselling to multiple patients at once, with or without a follow-up one-on-one session(s).
- 5) <u>Mainstreaming</u>: In the mainstreaming model, non-genetics clinicians provide pre-test information to their patients and obtain consent for genetic testing, which eliminates patient wait-times for pre-test genetic counselling in the genetics clinic. Post-test genetic services are built into this model, but may differ based on individual jurisdictions or contexts.
- 6) <u>Patient portals</u>: In the context of genetic counselling, patient portals are digital tools that have been developed and utilized for various purposes such as documenting pedigree information, performing risk assessments and providing education.
- 7) <u>Telehealth genetic counselling</u>: This includes individualized virtual genetic counselling either by telephone or by videoconference.
- 8) <u>Videos</u>: Patient education videos can be useful tools to address relevant genetics concepts both pre-test and/or post-test.
- 9) <u>Webinars</u>: A webinar is a live presentation that takes place virtually, allowing participants in different locations to see and hear the presenter, to ask questions and, possibly, to answer polls.

The detailed descriptions of the alternate models of genetic counselling service delivery in this document include, for each model, a summary of learnings, tips for getting started, points regarding accessibility and equity, cautions to consider and some accounts of Canadian success stories. A separate chapter with information regarding the evaluation of genetic counselling service delivery models is also included, as assessment of these models may be beneficial for research or justification purposes, or future revisions to the model. The goal in creating this document is to provide practical guidance for the CAGC membership should counsellors in any region across Canada wish to consider adopting novel models of care for their own practice.

Any change in healthcare practice comes hand-in-hand with challenges and undertakings in implementing new models of genetic counselling service delivery are no exception. Some noted barriers to developing novel models of care include time constraints, a lack of administrative, institutional or physician support and issues regarding funding and reimbursement for services. Approaches to new service delivery model selection and implementation are impacted by different institutional needs, available resources, and specific populations. Support from both institutional and clinic leadership, as well as collaboration with stakeholders (including patient partners), are all required to move forward constructively in implementing new models of service delivery. It is, however, reassuring to note the wide range and growing use of innovative models in Canadian genetic counselling services, despite the challenges involved.

Genetic counsellors are still a relatively young profession and, ever since their initial integration into health care teams, continual progression is underway in their training, practice and employment milieus. The rapid advancements in the field of medical genetics itself have pushed this evolution and will continue to propel further change and adaptation. It is not surprising that many Canadian genetic counsellors have already embraced new models of service delivery. The Alternative Models of Genetic Counselling Community of Practice group prepared the initial version of this document in 2024, knowing that the practice of genetic counsellors will continue to evolve and that other innovative models of genetic counselling service delivery may well be developed in the future. A review of these models, as well as newer developed ones, is planned in time, so that this document remains current and useful for CAGC members.